



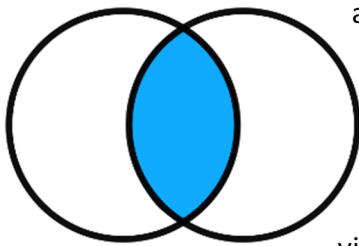
SSuN Best Practice Note

HIV Registry Matching

PS-24-0082 STI Surveillance Network Cycle 5 (SSuN)

This guidance applies to both Strategies A & B

Rationale



Registry matching is a vital aspect of SSuN, enabling the monitoring of HIV co-infection and comprehensive evaluation of HIV preventive services within sexually transmitted infection (STI) specialty clinical settings and among those diagnosed with acute STIs in the community. Patient self-report of HIV infection and HIV testing history can be unreliable, underscoring the importance of matching with the jurisdiction's HIV registry for the objective confirmation of HIV status. This process not only confirms an HIV-positive status but also provides insights into ongoing HIV care and viral suppression status through laboratory data reported to state and local HIV surveillance units.

In SSuN Cycle 5, routine and periodic HIV registry matching is required for all patients seeking care in collaborating STI clinics as well as for individuals diagnosed and reported with adult syphilis and/or gonorrhea. For patients who match a HIV registry entry, the earliest documented date of HIV infection and laboratory data (limited to specimen collection date and results of viral load [VL] and CD4+ tests) will be abstracted and included in SSuN datasets. The frequency of HIV registry matches will be determined based on local capacity, with a minimum requirement of matching twice annually. One match must coincide with SSuN's annual data submission in March of each project year, ensuring that results are included in the cumulative data for the previous calendar year. This periodicity ensures the timely integration of critical HIV-related data into the SSuN dataset, facilitating robust monitoring and evaluation of HIV-related services and outcomes.

Key Definitions

HIV Case Registry: For the purposes of SSuN, the term "HIV case registry" specifically refers to participating jurisdiction's eHARS (Enhanced HIV/AIDS Reporting System). Some jurisdictions may maintain supplemental case reporting or registry databases in synchrony with their official eHARS repository; these may provide similar functionality and validity to meet SSuN's requirements for HIV matching. If used for HIV registry matching in SSuN, these supplemental databases must be comprehensive, reflecting the full geographic scope of SSuN activities within the funded jurisdiction, and permit the extraction of required SSuN data elements, including HIV-related laboratory information.

Considerations for Implementation

The data required for matched patients, where a unique record exists both in the SSuN data and the HIV registry, are as follows:

- ❖ Date of earliest documented evidence of HIV infection.
- ❖ Specimen collection date and result for all quantitative VL tests performed on or after 10/1/2023.

- ❖ Specimen collection date and result for all CD4+ lymphocyte tests performed on or after 10/1/2023.
- ❖ HIV transmission category.

For matched patients with a unique record in both the SSuN data and in the HIV registry, local SSuN recipients may provide the following information back to their HIV surveillance unit:

- ❖ Date of patient visit or date of diagnosis with gonorrhea or syphilis.
- ❖ Information on the STI clinic visited or diagnosing provider for STI cases.
- ❖ Gender of sex partners from SSuN records, if known.
- ❖ HIV testing history from SSuN records, if known.
- ❖ Any patient- or provider-reported use of pre- or post-exposure prophylaxis (PrEP/PEP).

Key Considerations

As both HIV registries and the universe of SSuN patients are dynamic, with new patients being added continuously:

- ❖ All persons not previously matched should be re-matched throughout the project period.
- ❖ All persons previously matched with an HIV registry entry who present for subsequent visits at a participating STI clinic should be re-matched to update the patient's HIV laboratory (VL/CD4+) information.
- ❖ A separate person-index (often called a master patient-index) is a best practice for managing the input and output from matching activities. This would house the person-level identifiers and associated unique IDs from all sources for SSuN records, as well as maintain matching IDs from the HIV registry.
- ❖ SSuN patient and STI case lists used to match with the HIV registry MUST be de-duplicated prior to matching to the HIV registry.
- ❖ All processes involving HIV-related data must be approved by the jurisdiction's Overall Responsible Party (ORP) to ensure data security and confidentiality.

Best Practices

- ❖ All SSuN recipients should monitor HIV registry matching activities and meet regularly with their state or local HIV surveillance colleagues to assure that all requirements for data stewardship are maintained.
- ❖ The sensitivity and specificity of the HIV registry match should be assessed in collaboration with state or local HIV surveillance staff.
- ❖ Ongoing communication and collaboration between SSuN recipients and state or local HIV surveillance staff are essential for refining match processes and ensuring data integrity.



Creating and maintaining a 'master person index', which is a comprehensive file of unique person-based records from all SSuN activities, is a good way to assure that the results of registry matches are preserved. The master list should be de-duplicated when new records are added and results of matching runs documented here. This master list also can help assure that previously non-matched records are re-submitted to each new matching run.



Other Resources

- ❖ SSuN website: <https://www.cdc.gov/std/ssun/default.htm>
- ❖ No-cost matching software: <https://www.cdc.gov/cancer/npcr/tools/registryplus/lp.htm>
- ❖ NCHHSTP Data Security and Confidentiality Guidelines:
<https://www.cdc.gov/nchhstp/programintegration/docs/pcsidatasecurityguidelines.pdf>
- ❖ Program Collaboration and Service Integration White Paper:
https://www.cdc.gov/nchhstp/programintegration/docs/207181-c_nchhstp_pcsi-whitepaper-508c.pdf

CDC's Division of STD Prevention, Enhanced Surveillance and Special Studies Team created this series of documents for CDC staff working on PS24-0082 STI Surveillance Network (SSuN) and for applicants and recipients of that NOFO, to help clarify strategies outlined there and to support project implementation.

